



Antecedents of self-care in adults with congenital heart defects[☆]



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ABSTRACT

Background: Adults with congenital heart defects (ACHD) face long-term complications related to prior surgery, abnormal anatomy, and acquired cardiovascular conditions. Although self-care is an important part of chronic illness management, few studies have explored self-care in the ACHD population. The purpose of this study is to describe self-care and its antecedents in the ACHD population.

Methods: Persons with moderate or severe ACHD (N = 132) were recruited from a single ACHD center. Self-care (health maintenance behaviors, monitoring and management of symptoms), and potential antecedents including sociodemographic and clinical characteristics, ACHD knowledge, behavioral characteristics (depressive symptoms and self-efficacy), and family-related factors (parental overprotection and perceived family support) were collected via self-report and chart review. Multiple regression was used to identify antecedents of self-care maintenance, monitoring, and management.

Results: Only 44.7%, 27.3%, and 23.3% of participants performed adequate levels of self-care maintenance, monitoring and management, respectively. In multiple regression analysis, self-efficacy, education, gender, perceived family support, and comorbidities explained 25% of the variance in self-care maintenance ($R^2 = .248$, $F(5, 123) = 9.44$, $p < .001$). Age, depressive symptoms, self-efficacy, and NYHA Class explained 23% of the variance in self-care monitoring ($R^2 = .232$, $F(2, 124) = 10.66$, $p < .001$). Self-efficacy and NYHA Class explained 9% of the variance in self-care management ($R^2 = .094$, $F(2, 80) = 5.27$, $p = .007$).

Conclusions: Low levels of self-care are common among persons with ACHD. Multiple factors, including modifiable factors of self-efficacy, depressive symptoms, and perceived family support, are associated with self-care and should be considered in designing future interventions to improve outcomes in the ACHD population.

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1. Introduction

Fifty years ago only one third of children born with congenital heart disease survived to 10 years of age, but today 90% of children survive to adulthood and over one million adults are living with congenital heart disease (ACHD) [1,2]. Although the majority of adults had surgical repair in childhood, they are not cured. Surgical sequelae and residual defects cause late complications such as arrhythmia, heart failure, and the development of renal, pulmonary, and hepatic comorbidities [3]. With the exception of those with mild heart defects, complications are universal and require lifelong surveillance and illness management. Although self-care is a vital component of chronic illness management, little is understood about the practice of self-care in ACHD. A small number of studies have provided beginning evidence indicating that low levels of self-care may be a significant problem for persons with

ACHD. Between 40 and 60% of adults, for instance, are not engaged in routine care [4,5], and up to 85% do not meet physical activity recommendations [6]. Further, at least 20% of women do not attend pregnancy counseling despite high rates of maternal and fetal complications [4,7].

Lower levels of self-care have been associated with poor health outcomes. In ACHD, those with a three-year lapse in care are over three times more likely to require emergent interventions, receive additional diagnoses, and experience more symptoms [5], and those who are less physically active have greater reductions in functional capacity [8]. Thus, improving self-care may be an effective means of reducing ACHD morbidity, but the development of interventions to promote self-care is limited by the lack of evidence regarding antecedents of self-care in this population. Few have studied ACHD self-care behaviors and there is no consensus on the individual and clinical factors that may explain self-care. Furthermore, no studies of self-care in an adult cohort of patients with congenital heart disease have examined typical antecedents important in other chronically ill populations such as knowledge, behavioral characteristics of self-efficacy or depressive symptoms, and social support. The purpose of this study is thus to

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describe the practice of self-care and identify possible antecedents of self-care, so that meaningful interventions to improve self-care behaviors can be designed for the ACHD population.

2. Methods

Given its holistic perspective and utility in the similar acquired heart failure (HF) population, antecedent factors were chosen based on the Family and Self-Care Framework (Fig. 1), including individual, clinical, behavioral, and family-related factors [9]. A cross-sectional, descriptive study design was used to describe self-care and to determine the relationship antecedent factors and self-care.

2.1. Sample and setting

After receiving IRB approval, all eligible adults were recruited from a large ACHD clinic located in the southeastern US. Eligible adults were identified through medical chart review and recruited directly from clinic appointments. Inclusion criteria included 1) aged 18 years and older, 2) having moderate or severe CHD per American Heart Association/American College of Cardiology guidelines [10], and 3) English-speaking. Exclusion criteria were 1) developmental delay impairing ability to independently complete surveys, 2) adult diagnosis of ACHD, and potential confounders of a walking test including 3) current pregnancy, 4) disability preventing ability to walk, and 5) less than one month post-op from cardiac surgery. A total of 341 persons were screened for eligibility; 168 (49%) did not meet inclusion criteria and 23 (12%) declined participation. Of the 150 patients consented, 132 (88%) completed baseline data collection.

2.2. Procedures

Once informed consent was obtained, participants completed a six-minute walk test (6MWT) and received study surveys. Participants completed surveys at the clinic appointment or at home either electronically via a secure, electronic database survey system or via paper surveys. Clinical information was collected via medical chart review. Participants were compensated with a parking voucher and \$10 gift card.

2.3. Measurement

2.3.1. Self-care

Self-care was operationalized as three separate constructs: maintenance (behaviors that maintain physiologic stability), monitoring (attention to changes in symptoms), and management (response to symptoms when they occur). Self-care was measured using the 32-item Self-care Index for ACHD (SCI-ACHD), a modified version of the Self-Care in HF Index [11]. Subscales of self-care maintenance, monitoring, management (completed only by persons experiencing heart-related symptoms in past month), and self-care confidence were scored independently. Scores were standardized on a 100-point scale with higher scores reflecting higher levels of self-care.

2.3.2. Individual and clinical characteristics

Sociodemographic variables (age, gender, race, educational level, marital status, employment status, and insurance status) were collected by self-report. Clinical variables

(type and severity of heart defect, NYHA Class, comorbidities) were collected via medical chart review. Severity of heart defect was classified as moderate or severe based on AHA guidelines [10]. The Charlson Comorbidity Index (CCI), widely used in the acquired HF population was used to measure comorbidity severity [12].

2.3.3. ACHD knowledge

ACHD knowledge was measured using a 22-item survey developed by the investigator and based on the ACHD Patient Health Passport, a 7-page booklet used to store personal health information, including health history, health risks, and self-care needs [13]. All questions are scored as correct or incorrect, summed for total score and then standardized on a 100-point scale.

2.3.4. Behavioral characteristics

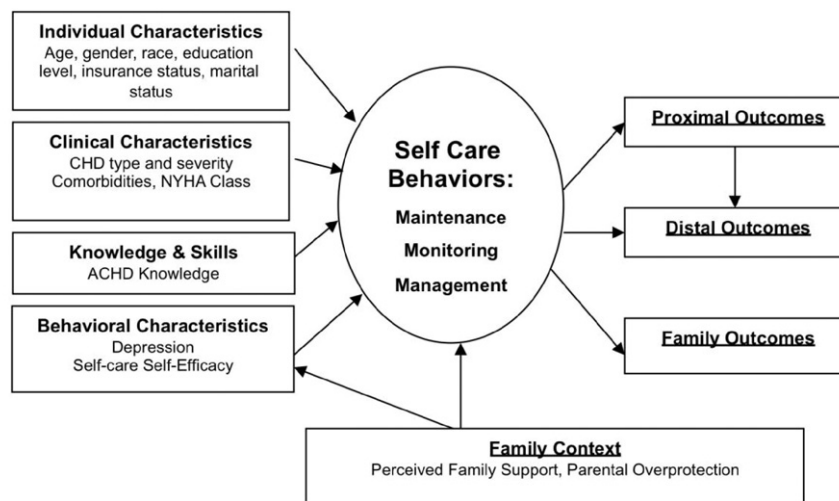
Behavioral characteristics evaluated in this study included depressive symptoms and self-care self-efficacy. Depressive symptoms were measured using the Patient Health Questionnaire-9 (PHQ-9), a widely used 9-item, self-reported scale [14] with excellent reliability in ACHD populations (CA of 0.88) [15]. Self-care self-efficacy, or perceived confidence in self-care ability, was measured using the 6-item self-care confidence subscale of the SCI-ACHD.

2.3.5. Family factors

Family factors measured in this study included family self-care self-efficacy and parental overprotection. Family self-care self-efficacy, or perceived support for self-care from family, and was measured using the 4-item Stanford Chronic Illness Family, Friends, and Community Self-Efficacy Scale [16]. Language related to friends and community was removed from questions so that family remained the only support mechanism. Parental overprotection, a rating of attitudes and behaviors of parents in the first 16 years of life, was measured using the Parenting Bonding Inventory Overprotectiveness subscale [17], a 13-item scale with excellent reliability in the ACHD population (CA = 0.89) [18].

2.3.6. Data analysis

Descriptive statistics were analyzed for all study variables. All instruments were scored in accordance with author guidelines and Cronbach's α was calculated for the instruments not previously tested in the ACHD population. Bivariate relationships between individual, clinical, knowledge, behavioral, and family antecedents and each self-care construct (maintenance, monitoring, management) were determined using Pearson's correlation. Multivariate stepwise regression analysis was used to statistically evaluate the relationship between antecedent factors and each self-care construct. All antecedent factors (age, gender, race, education, insurance status, marital status, CHD severity, comorbidities, NYHA Class, depressive symptoms, self-care self-efficacy, parental overprotection, and perceived family support) were included in regression analysis. Factors entered the model at a .10 level of significance and stayed in the model at a .05 level of significance. Dichotomized data was used for race (white, nonwhite/other), education (high school graduate, any college or more), insurance status (private, public/uninsured), marital status (married/living with partner, widowed/divorced/single), and NYHA Class (I/II, III/IV). Multicollinearity was tested for in each regression model and no confounding was present (variance inflation factor <2). All data was analyzed using SPSS version 22 and an alpha set at 0.05.



*Adapted from the Family and Self-Care Framework for HF¹⁶

Fig. 1. Family and self-care framework for ACHD. Adapted from the Family and Self-Care Framework for HF¹⁶.

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